

# BENO



## BIO Quarterly

A Publication of  
The Bioethics  
Network of Ohio

### ● 28th Annual BENO Conference Recap



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**H**eld Friday, April 27th, 2018 at the OCLC Conference Center, the BENO annual conference focused on the Intersection of Bioethics and Disability and boasted over 110 attendees. This year’s annual conference comprised three general sessions and five different breakout sessions addressing a variety of pressing ethical issues in contemporary medical care. In her keynote address, “Forgoing Life-Sustaining Medical Treatment in Children: What’s New Since



1994?”, Kathryn Weise addressed the American Academy of Pediatrics’ initial guidelines for withdrawing/ forgoing life-sustaining treatment, and why it was important to review and update those guidelines. In the intervening years since the “Baby Doe” case, the advances in potential treatments have only complicated what was already a difficult decision.

Dr. Weise addressed this increasing complexity of involving multiple stakeholders, as well as new sources of family knowledge (i.e., social media), and the importance of shared decision-making. The updated guidance continues to reflect a strong presumption in favor of sustaining life, but also a recognition that withdrawing life-sustaining treatment

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### Bio Quarterly

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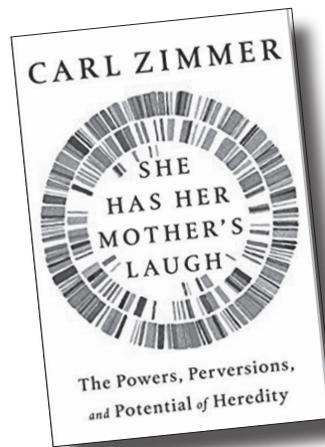
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## ● Ethics Book Corner

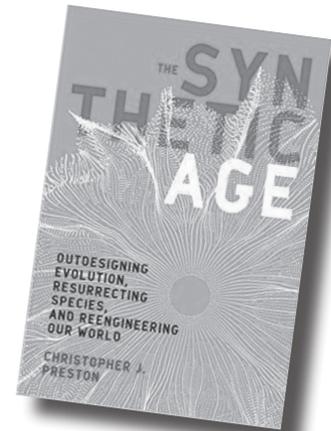
### ***She Has Her Mother's Laugh: The Powers, Perversions, and Potential of Heredity*** by Carl Zimmer



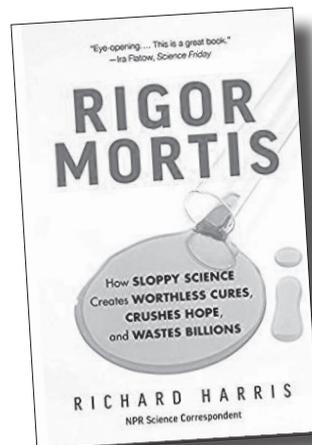
In the age of 23andMe, Ancestry.com and others, there has been increasing speculation and questions as to the ethical nuances of widely available genetic testing. This book strives to answer questions about what it fundamentally means to inherit traits and how one's own genetic makeup may change every day, bearing new questions about the meaning of the word "hereditary".

### ***Synthetic Age: Outdesigning Evolution, Resurrecting Species, and Reengineering our World*** by Christopher J. Preston

Now that there are no longer any places on Earth that are untouched by human influence, we must go on to speculate on what our world's metabolism will look like when humans actively engineer new aspects of what used to be natural biological life. In this book, humanities professor Christopher Preston imagines what sort of ethical implications it will have as humans shift from being global stewards to active managers and synthesizers of solutions to its problems.



### ***Rigor Mortis: How Sloppy Science Creates Worthless Cures, Crushes Hope, and Wastes Billions*** by Richard Harris



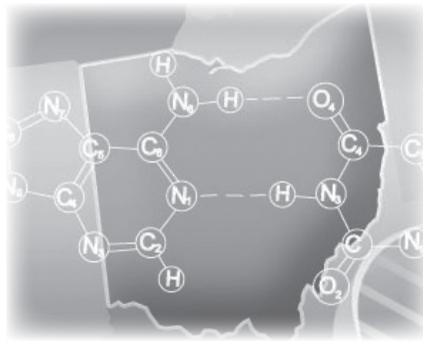
This critique on the biomedical research industry expounds on many unsung problems that have led to a lack of groundbreaking medical therapies in recent years. Particularly, author Richard Harris highlights the toxic competitive culture in many labs across the United States which force scientists to publish subpar data, which turns out to be irreproducible and clinically inapplicable.

**28th Annual BENO Conference Recap** *continued from page 1...*

is ethically supportable when the burdens of continued treatment outweigh the benefits to the child. Dr. Weise reminded attendees that keeping the child as the common focus is the most important thing, even when stakeholders disagree about what the best course of care is.

BENO's president, Cassandra Hirsh, herself an experienced pediatric palliative care physician, facilitated a panel discussion about young adult patients with chronic illness who are transitioning from the pediatric care context to the adult one. Dr. Hirsh's panel drew on the insights of a fellow clinician, the parent of a young adult with a chronic illness, and a young adult patient with a chronic illness with a personal interest in ethics. Attendees benefitted from the insights on the complexities and challenges from several first-hand perspectives.

In the morning and afternoon breakout sessions, Barbara Wojtala of the Cleveland Clinic presented a breakout session on patients whose needs were not best met in a hospital setting who nevertheless frequently accessed hospital systems and what can be done to address these challenges. Wojtala described an Individualized Plan of Care Committee that seeks to actively identify such patients in order to supply these patients with plans of care that address their needs while reducing reliance on hospital-level care. Rabbi Stephanie Covitz, a chaplain at OhioHealth Rehabilitation Hospital, presented on patients with temporary and enduring disabilities can and should be supported during their care and healing processes. Drawing on her experience caring for this specific patient population, Covitz urged that spirituality could help patients come to terms with new, temporary, chronic, or permanent limitations; Covitz reminded attendees that the spiritual dimensions of personhood are not exhausted by identification with, or participation in, organized religion and that many patients who were not explicitly religious might still benefit from the spiritual support afforded by chaplains. Karen Huelsman of the TriHealth Cancer Institute reviewed numerous topics in genetics with salience to biomedical ethics, ranging from billing practices to post-mortem genetic testing. Monica Gerrek, Alan Murphy, and Steven Squires offered lessons learned from four very different health systems and numerous care sites within those health systems. Attendees heard that ethics committees at institutions with robust clinical ethics consultation services can be productively employed



as venues for outreach and integration with the wider care site, while committees at care sites without full-time ethics consultants have benefited from thoroughly thought-out, systematized educational programs to build competence. And on the note of competencies central to clinical ethics, Corey Perry from OhioHealth facilitated two sessions on mediation in the context of clinical ethics. Perry reviewed the relevant skills and helped participants practice these skills in the context of a case study drawn from practical experience in providing clinical ethics consultation.

Cristie Cole and Joshua Crites, both past mentees of this year's Founder's Award winner Marty Smith, spoke at the Founders' Plenary on the topic, "Protecting and Promoting Patients: Ethics' Role in Working with Guardianship and Patients without Surrogates." This is a particularly difficult

issue encountered by virtually all adult hospitals in the state, and as Cole and Crites reported, there are an increasing number of patients in this category. The presentation focused on patients who (1) lack decision-making capacity, (2) do not have any advance directives, and (3) do not have an authorized surrogate decision-maker. Cole and Crites discussed Ohio's statutory remedy, guardianship, while cautioning that

several concerns — the amount of time required to obtain a guardianship among the most common — can combine to make guardianship an impractical or inappropriate option for many patients without surrogates. The presenters discussed the different ways other states have addressed this issue. Cole and Crites recommended that teams treating these patients employ a process involving a fair and patient-centered interdisciplinary effort, including vigilant capacity assessments, the diligent search for potential surrogates, as well as robust information gathering to ascertain patient values.

As this synopsis suggests, this year's conference afforded attendees the opportunity to learn about diverse topics in bioethics while making new connections (and renewing old ones!) with those engaged in this work throughout the state. If you missed this year's conference, please keep an eye on *Bio Quarterly*, [benoethics.org](http://benoethics.org), and your e-mail for information about next year's conference; you can expect a notice to "save the date" by the end of calendar year 2018. Although this year's conference is only months past, initial planning is already underway for the next one to ensure that it, too, will be a great event.



broad agreement on substance. Engelhardt anticipated this as well: “to what kind of moral standards should a hospital be held if it belongs to no particular moral tradition and serves physicians and patients from diverse faith traditions, as well as those who belong to no religious tradition at all? [6]” In Engelhardt’s view, “this can be determined ‘in non-religious terms by appeal to what we share as humans,’ . . . [as such,] “every healthcare system will therefore be a compromise. It will represent what individuals can agree to support with their common goods. [7]” This outlook, however, is based upon excerpts in *Foundations* (1986) and the assumptions underlying secular morality as expressed by Engelhardt.

Despite criticisms of it, secular humanism along the lines Engelhardt described has been put to work in bioethics. David Schiedermayer, in *The Last Physician* (1999), describes the case of one of his patients, 10 weeks pregnant, who requested an abortion due to a pulmonary embolus, the treatment of which would threaten the health of the fetus. Although her physician was morally opposed to abortion, citing his faith, he provided the procedure as it was the patient’s legal right. After the abortion took place, he revisits to check in on her. As he sat down to talk, he saw the Bible next to her bed stand. Recalling that exact moment he states, “I don’t feel guilty or ashamed, and she doesn’t either; you can see it. But I do feel somehow as if I have avoided something, as if I have turned my eyes away, turned my eyes away, turned my eyes away. [8]” While this example is of difficult discussion, especially those with strong moral convictions, it reveals a ‘compromise’ the healthcare system took between religious and secular ethics. Her physician privately holds a deep conviction against abortion practices, and him seeing the Bible but “turning his eyes away” harkens back to Engelhardt’s moral vision of secular bioethics: doctor and patient achieved moral agreement outside of religious ethics in a secular pluralistic society.

***In an era of medical practice when cultural competency is becoming increasingly recognized as critical to excellent care, we must learn to consider our own personal value systems, whether they be religious or secular, as only one part of the solution in solving an ethical dilemma.***

In an era of medical practice when cultural competency is becoming increasingly recognized as critical to excellent care, we must learn to consider our own personal value systems, whether they be religious or secular, as only one part of the solution in solving an ethical dilemma. In this way, we will be able to better achieve common ground with other healthcare providers, ethicists and our patients. Engelhardt has not only left us with knowledge to better understand a pluralistic world in which we all live in, but a moral vision that suggests we can agree to disagree still while tolerating and respecting one’s own way of life.

***In Honor of the Late H. Tristram Engelhardt Jr., PhD, MD – The most brilliant American philosopher of our time. (1941-2018)***



[1] Engelhardt, H. Tristram. *The foundations of bioethics*. New York: Oxford University Press, 2005.

[2] Ibid.

[3] Ibid.

[4] Iserson, Kenneth V. “Bioethics and Secular Humanism: The Search for a Common Morality.” *JAMA*. 267, no. 6 (1992).

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## ● What Are Physicians' Responsibilities to Patients Whose Health Conditions Can Influence Their Legal Proceedings?

Commentary by David Beckmann, MD, MPH (*Reprint from JAMA Journal of Ethics, September 2017 Issue; edited for length*) What Are Physicians' Responsibilities to Patients Whose Health Conditions Can Influence Their Legal Proceedings?



**David Beckman, MD., MPH** is a fellow in child and adolescent psychiatry at Massachusetts General Hospital and McLean Hospital and a clinical fellow at Harvard Medical School in Boston. He is interested in correctional psychiatry and helped to create a new residency rotation at a Boston jail, where he works as the mental health faculty advisor and preceptor for a student-faculty collaborative clinic.

### Case

**D**r. Obaje is a primary care physician who works at a county jail, where most of her patients are undergoing court processes. Jonathan, a 52-year-old man with a known history of poorly controlled type II diabetes and a 20-year history of opioid use, is brought to the jail's medical ward for a routine chronic care visit. This is the first time that Dr. Obaje has met Jonathan since his incarceration four weeks ago. Jonathan's blood sugars have ranged between 80 and 150 since his incarceration, and he does not currently seem to be experiencing any withdrawal symptoms. However, during the appointment, Jonathan struggles to provide a health history, shares tangential information, and repeats some information several times. After Dr. Obaje briefly leaves the room to answer a nurse's question, Jonathan does not appear to remember having met her when she returns.



Based on this memory lapse and Jonathan's history, Dr. Obaje worries that Jonathan could be exhibiting cognitive impairment. Jonathan reports that he has been transiently homeless during the past decade and that during several

periods of homelessness he experienced violence, including blows to the head. She asks Jonathan about his mood, and he confirms that he "often feels down" and states that "sometimes I get so angry, and I'm not sure why." On the Mini-Mental State Examination, Jonathan receives a score of 21 out of 30, and Dr. Obaje diagnoses him with mild cognitive impairment (MCI) [1].

Dr. Obaje refers Jonathan for mental health care not only for treatment but also to rule out reversible causes of cognitive decline. She also asks her mental health colleagues to evaluate how Jonathan's cognitive impairment influences his decision-making capacity and judgment. Dr. Obaje wonders whether information about Jonathan's cognitive symptoms could be important for his legal defense.

### Commentary

Medical and mental health clinicians working in the correctional setting are likely to encounter scenarios similar to Dr. Obaje's encounter with Jonathan. Conditions that might be associated with cognitive impairment, such as aging, are common in correctional settings. Between 2-3 percent of people incarcerated in jails are over the age of 55, a proportion that is expected to increase as the population ages [2-4]. While risk of cognitive impairment is highest for persons over age 65 [5], inmate populations might have more risk factors for dementia and other cognitive impairments, and their prevalence is likely higher in inmate populations than in the general population [3]. In 2002, 19 percent of people incarcerated in jails met criteria for substance use disorder; 15 percent met

criteria for other mental health problems; and about half met criteria for both [6]. Any mental illness might have effects on cognition, particularly serious mental illness (SMI) that causes severe functional impairment—such as schizophrenia, bipolar disorder, or major depressive disorder [7]—which is estimated to affect up to 19 percent of men and 42 percent of women incarcerated in jails [8]. The prevalence of traumatic brain injury (TBI) in correctional settings is also likely higher than that of the general population [9]. Thus, Dr. Obaje’s meeting a relatively young patient with cognitive difficulties is not unusual, but it remains a practically and ethically complex situation.

What is key to Dr. Obaje’s relationship with Jonathan is that she is his treating clinician, and therefore her primary responsibility is to her patient and his best interests. The same is true of the psychiatrist to whom she refers Jonathan for further diagnostic and treatment management. The concept of patient-centered care—the idea that clinicians should help patients be active, informed participants in their own medical management—is, if anything, more important in settings where patients are already marginalized. In the correctional setting, where the rights and freedoms of patients are already severely restricted, fostering patient agency so that patients can make informed decisions about their care is essential.

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This commentary will consider a number of ethical issues in this case. First, privacy and informed consent will be discussed. Then the application of standard bioethical principles in surrogate decision making and standards of surrogate decision making will be considered in relation to the case. Finally, how clinicians might interact with other third parties, such as legal counsel, forensic evaluators, and correctional staff, will be considered.

## Privacy and Informed Consent

Although there are some differences in the care of patients in the correctional setting (such as the duty to inform custody staff about contraband), laws addressing health care communication and privacy, such as HIPAA, apply in the same way [11]. Without a patient’s consent, clinicians may only share medical information to a third party for treatment, payment, or health care operations; disclosure to legal counsel is not included in these criteria. The easiest thing for Dr. Obaje to do is to discuss with Jonathan the possibility of her informing his counsel of her concerns.

However, if Jonathan does not consent—or even if he does—things are a bit more complex. This is because the nature of his illness might impair his ability to give informed consent (either to permit or to forbid the doctors’ speaking to his attorneys). What does not substantially change the importance of consent—or, in Jonathan’s case, the assessment of his ability to do so—is the fact that Jonathan is incarcerated. There is no legal reason for incarceration to change the process of consent as it relates to medical care.

## Assessment of Decision-Making Capacity and Surrogate Decision Making

Regardless of Jonathan’s decision, any involved physician should determine if he has decision-making capacity. Determination of capacity is a clinical decision that may be made in any treatment setting and is distinct from determination of competence, which is made by a judge and relates to a person’s longitudinal global functioning, although the exact legal definition is variable by jurisdiction [12].

If Dr. Obaje feels that Jonathan does not have decision-making capacity to consent to her communicating with his legal team about his MCI, she must apply the bioethical principles of beneficence and respect for autonomy in deciding what to do. A frequently invoked standard for decision making in such cases is that of substituted judgment: the clinicians and family members make a decision based not necessarily on what they feel is best for the patient, but rather on what they believe the patient

*continued on page 8...*



would have wanted if able to make decisions. In Jonathan's case, if close contacts are not available, Dr. Obaje might be in the position of having to decide what decision he would have made, and acting accordingly. Some patients might be more averse to the idea of having a mental illness, or of being in a treatment facility that addresses mental or cognitive difficulties, than to a harsher criminal sentence; it is well documented that the stigma of psychiatric illness is magnified in the correctional setting due in part to some correctional officers, who may treat incarcerated patients with psychiatric illness with disrespect or disregard for their vulnerabilities [14]. If Dr. Obaje has no information about Jonathan's preferences and is unable to predict what decision Jonathan would have made, she cannot apply the standard of substituted judgment and instead should apply the best interest standard. For example, she might determine that she should inform his counsel of

her concerns, given the benefits of this course of action to Jonathan (i.e., potentially getting Jonathan into a treatment environment rather than a correctional one).

In making this determination, Dr. Obaje has a potential source of assistance. Dr. Obaje was able to gain consultation from a jail psychiatrist, who might be able to provide additional perspectives as to Jonathan's decision-making capacity. Clinic leadership, such as a mental health director or a medical director in a correctional clinic can also be valuable resources for consultation. Getting information from multiple sources and perspectives might make Dr. Obaje feel more confident in her diagnosis or her course of action. It is worth noting, however, that diagnostic certainty is by no means a prerequisite to sharing potentially relevant information with a patient's legal counsel.

### Sharing Protected Health Information

The benefit of Dr. Obaje sharing her concerns with Jonathan's counsel is so that his defense team can argue that his MCI should be taken into account during his trial. One way that a lawyer (or the judge) might introduce this information is through the use of a **forensic evaluator**. The explicit role of a forensic evaluator is to opine on how the patient's illness or limitations might affect his charges or mitigate sentencing. The roles of treating clinician and forensic evaluator are intentionally kept separate whenever possible to avoid conflicts of interest [15]. Jonathan's attorneys, however, were they made aware of his MCI, might respond by obtaining an independent forensic evaluation to strengthen the legal case that his MCI should be taken into account. It will probably ultimately be the role of someone appointed through his lawyers or the judge—namely, a forensic evaluator—to determine the appropriateness of any diagnosis and how it should impact legal proceedings and decisions.

While there are no laws requiring clinicians to disclose protected health information to a patient's counsel, the American Bar Association requires that the attorney act as a "zealous advocate" for his or her client [16]. As with any sharing of medical information, Dr. Obaje should reveal the minimum amount necessary to achieve the purposes of the communication. Details that would not

affect an attorney's decision to get a forensic evaluator, or which would not be relevant to such an evaluation, should not be shared. Although there is no obligation for her to speak to the defense counsel in this situation, she could disclose information that might help Jonathan if she has his permission; or, in the event that Jonathan lacks decisional capacity, Dr. Obaje should obtain consent from a surrogate decision maker or make a decision based on substituted judgment or his best interests. On the other hand, his council is obligated to consider if involving a forensic evaluator would be in Jonathan's best legal interest.

***Mental illness and cognitive impairment are risk factors for being victims of violence from both other inmates and correctional staff***

Finally, there is an additional consideration in decisions about sharing information about Jonathan's mental state. Separately from sharing this information with his defense team, should Dr. Obaje's concerns be shared with the correctional staff? There is reason to believe that her concerns about Jonathan's mental status warrant his being treated differently from other inmates. This is particularly true if any jail or medical staff members believe that Jonathan's condition puts him at increased risk of victimization from other inmates. Mental illness and cognitive impairment are risk factors for being victims of violence from both other inmates and correctional staff [5, 17]. In many correctional settings, this risk of violence can be mitigated by putting the inmate in a different setting (either in the same facility or in a different facility). If this is not possible, Dr. Obaje might explain to correctional staff that Jonathan's condition warrants his receiving extra protection. There is little legal guidance on how she should balance her concerns for her patient's privacy and well-being in her discussions with correctional staff, although some professional guidelines have been proposed [18]. However, the jail itself is legally obligated to afford Jonathan additional protections if he is at increased risk of victimization, even if only from other incarcerated persons, and failing to protect him from this increased risk of harm is a violation of his constitutional rights.



## Conclusion

This is a complex but realistic scenario similar to situations that physicians working in the correctional setting are likely to encounter. From a legal perspective, a clinician's ethical obligations to a patient with a mental illness or cognitive impairment do not change markedly because he or she is in correctional custody. However, the implications of incarceration should still be considered. Some clinicians

***From a legal perspective, a clinician's ethical obligations to a patient with a mental illness or cognitive impairment do not change markedly because he or she is in correctional custody.***

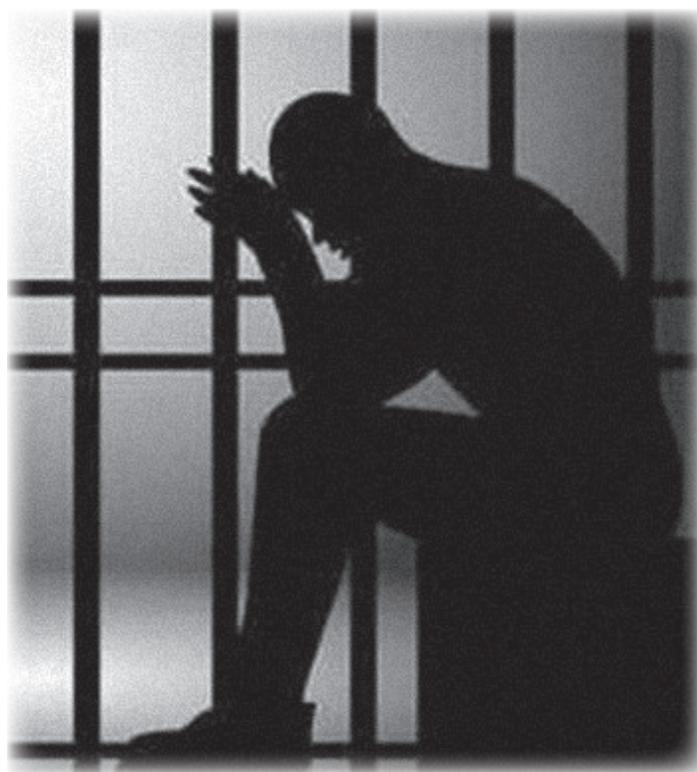
might have a tendency to partition the lines between the legal and medical systems as much as possible to avoid overstepping their bounds; this compartmentalization might make physicians in the correctional setting less likely to take actions that might be considered effective advocacy for their patients. However, the alternative must also be considered: patients in correctional custody are stripped of so many of the rights and comforts afforded to our patients in the civilian world that going the extra mile to advocate for an incarcerated person's care might have significant benefits for his or her health care, legal situation, and overall well-being.

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In this scenario, Dr. Obaje should explain to Jonathan her belief that he has MCI and that this knowledge could help his legal counsel in defending him. She should ask his permission to share this information; whether or not he provides permission, she should also assess his decision-making capacity to do so. If he has capacity to give consent, his preference should be honored. If he does not, she should try to make a decision based on substituted judgment and tell his attorney that this is what he would have wanted were he not impaired. If he lacks capacity and she is unable to make a substituted judgment due to lack of available information, she should do what is in Jonathan's best interest—which, in this case, means informing his defense counsel.

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## Upcoming Conferences



### **Innovations in Clinical Ethics: A Working Un-Conference: August 26-28, 2018.**

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Western Michigan University, Kalamazoo, MI. For more information, see: <https://wmich.edu/medicalhumanities/events/conference2018>

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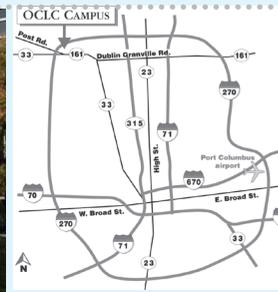
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*Serving Ohio as an educational resource in healthcare ethics.*

**Save the DATE!** 

Bioethics Network of Ohio  
**29th Annual Conference**

**April 26, 2019**



**The Conference Center at OCLC • 6565 Kilgour Place • Dublin, Ohio 43017**